

Findings from the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC): Changes in the Prevalence of Autism Spectrum Disorders in Newfoundland and Labrador, Prince Edward Island, and Southeastern Ontario

The **National Epidemiologic Database for the Study of Autism in Canada (NEDSAC; www.nedsac.ca)** was established as a way to track the number of children diagnosed with an autism spectrum disorder (ASD) in different regions of Canada. ASDs currently include autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger disorder.

We examined the proportion of children 2–14 years of age with an ASD (the prevalence) based on information from NEDSAC surveillance programs in Newfoundland and Labrador (study period 2003–2008), Prince Edward Island (2003–2010) and Southeastern Ontario^a (2003–2010). In these regions, a total of 700 (Newfoundland and Labrador), 269 (Prince Edward Island), and 1408 (Southeastern Ontario) children with ASDs were identified in at least one year of the study period. A full report of the findings is available on our website at www.nedsac.ca (click on the Publications tab and look under Reports → NEDSAC Update 2012). The main findings from the report are shown below. In some instances, we compare our findings with those from the Autism and Developmental Disabilities Monitoring (ADDM) Network, a surveillance program for ASDs in various American states that is funded by the Centers for Disease Control and Prevention.

- **The prevalence of ASDs increased in all age groups (2–4 years, 5–9 years, 10–14 years)** in all regions. The percent increases in prevalence based on a comparison of the first and last years of the study period ranged from 39% to 204%.
- **The percent change in prevalence was higher for boys than girls in Newfoundland and Labrador and Prince Edward Island** (87% versus 63% and 111% versus 18%, respectively). The ADDM Network reported that the average change in prevalence between 2002 and 2006 was 60% for boys compared to 48% for girls.¹ It noted that the most consistent pattern across sites was the increased prevalence among boys, and suggested this may reflect a growing risk among males (although it cautioned that more data are needed to evaluate this). In contrast, the ADDM Network found more variation in prevalence changes among girls between 2002 and 2006. Such variation could be due to improved recognition of ASD symptoms in girls rather than an increase in risk.¹
- **In Southeastern Ontario, the prevalence among the younger age group (2–4 years) appeared to be levelling off** in the final years of the study period, and in Newfoundland and Labrador the prevalence decreased between the last two years of the study period for this age group. Prevalence trends should be monitored in younger age groups born at a time when awareness of autism was already high; evidence of a continued increase in prevalence in these groups would provide greater support for a true increase in the occurrence of ASDs.^{2,3} A changing age at diagnosis could affect the measured prevalence in younger children, however, so monitoring trends to see if there is any levelling off of

^a Includes the six counties of Hastings, Prince Edward, Lennox & Addington, Frontenac, Lanark, Leeds & Grenville

prevalence should include children older than 4 years of age. **No levelling-off effect was observed in Prince Edward Island for any age group.**

- **In Newfoundland and Labrador and Prince Edward Island, the prevalence in the final year of the study period for children 5–9 years of age (1 in 93 and 1 in 106, respectively) was higher than the average prevalence reported by the ADDM Network for 8-year-olds in 2006 (1 in 110).¹** However, a recent study found that 1 in 77 8-year-olds living in Utah was identified with an ASD in 2008.⁴ The prevalence among children 5–9 years of age was much higher in Southeastern Ontario (1 in 63) than in the other regions, but we suspect this may be partly due to agencies failing to inform us when children moved from the region.
- **The boy:girl ratios changed more in Prince Edward Island** than in the other two regions, but all ratios were consistent with the range reported by the ADDM Network for its 2006 surveillance year (3.2:1 to 7.6:1).¹
- Our data suggest that a **substantial proportion of children (44%–56%) were not diagnosed until after their fifth birthday.**
- **An earlier age at diagnosis did not appear to explain the increases in prevalence** in any of the three regions. **Greater detection of children on the milder end of the spectrum may have contributed to increases in prevalence in Newfoundland and Labrador.**

Please see the full report at www.nedsac.ca. Thank you to everyone who provided information for this project!

1. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2006 Principal Investigators. Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorders — Autism and Developmental Disabilities Monitoring Network, United States, 2006. *Morbidity and Mortality Weekly Report Surveillance Summaries* 2009; 58(10): 1-20.
2. Hertz-Picciotto I, Delwiche L. The rise in autism and the role of age at diagnosis. *Epidemiology* 2009; 20(1): 84-90.
3. Rice C, Nicholas J, Baio J, Pettygrove S, Lee LC, Van Naarden Braun K, et al. Changes in autism spectrum disorder prevalence in 4 areas of the United States. *Disability and Health Journal* 2010; 3(3): 186-201.
4. Pinborough-Zimmerman J, Bakian AV, Fombonne E, Bilder D, Taylor J, McMahon WM. Changes in the administrative prevalence of autism spectrum disorders: contribution of special education and health from 2002-2008. *Journal of Autism and Developmental Disorders* 2012; 42(4): 521-530.

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